HAUTE AUTORITÉ DE SANTÉ

RECOMMEND BEST PRACTICES

SUMMARY

Supporting and encouraging public engagement in social and health care organisations

Validated by the HAS Board on 23 July 2020

Key points

- The engagement* of stakeholders[1] needs to be encouraged and supported by decision-makers and managers in health and social care organisations.
- For each project or situation, the aim is to achieve the highest possible level of engagement. However, it is necessary to adjust to the contexts and possibilities of both stakeholders and professionals.
- Providing methods for recognising engaged people is a factor in the sustainability of the actions. These methods include: the definition of statuses, reimbursement of expenses, methods of compensation or remuneration and validation of acquired experience.
- This approach requires the affirmation of strong principles and the provision of appropriate resources: time, funding and a dedicated support unit.
- Research and evaluation studies on engagement need to be developed.
- It is intended that this guideline be supplemented by documents or tools appropriate to the various contexts and activities in order to facilitate its implementation. It is intended to evolve over time to take into account feedback and necessary innovations.

[1] In this text, the term "stakeholder" refers to any person concerned by a social or health problem and/or any person seeking a health, social or preventive service, as well as their relatives, carers and/or representatives*.

* The words followed by an asterisk are defined in the glossary appended to this recommendation [in French].

Definition

In social and health care organisations, stakeholder engagement refers to any form of action, be it individual or collective, for the benefit of their health, well-being or quality of life, or that of their peers.

This engagement in turn requires the engagement of professionals and decision-makers to ensure that the experience, needs and preferences of stakeholders are considered, both in health and social care and in the improvement of practices and organisations, as well as in teaching and research.

This joint engagement contributes to a better service for stakeholders and their increased empowerment.

Values to be clarified and principles to be respected

- The joint engagement* of decision-makers, professionals and stakeholders is based on the principles of mutual recognition, sharing of knowledge and power, and respect for the rights of individuals.
- From the outset of a project in which professionals and stakeholders are jointly engaged, it is recommended:
  - to identify the values and ethical principles uniting the different parties, to explore their respective meaning for each party and the practical implications for the project. It is necessary to maintain this vigilance with respect to these values throughout the project. The actions described in the literature concerning engagement or participation* are notably carried out in the name of citizenship, self-determination*, respect for equality, autonomy*, and individual dignity;
  - to mutually recognise the competencies* and knowledge of each party. In particular, recognise that an individual who is a user of the healthcare system or of a social care institution or service develops knowledge from this experience* which has no less value or legitimacy than academic knowledge. These two types of knowledge are complementary and must be combined to enable mutual learning.
- To support stakeholder engagement, it is recommended to draw on the following principles:
  - recognise that it is always legitimate for individuals to make their own decisions, whatever their situation, in conjunction with their legal representatives where appropriate. Thinking, saying and doing in the place of stakeholders is an infringement of their dignity and rights;
  - give precedence to the will and preferences* of stakeholders in decisions concerning them, unless there is a regulatory exception (e.g. care without consent);
  - recognise that the following elements are important sources of well-being: developing empowerment*, the feeling of “being capable”, having the possibility to intervene in something that is meaningful to you, not having to endure;
  - consider the engagement of professionals and stakeholders as a partnership*. To avoid token participation*, the notion of partnership requires a relationship based on mutual trust, transparency, respect, non-judgement and clarification of the division of powers and responsibilities.

- To support the engagement of people being cared for or supported, the following operational principles are recommended:

* The words followed by an asterisk are defined in the glossary appended to this recommendation [in French].

- make sure you are inclusive*, i.e.: support the engagement of people who feel excluded from spaces for dialogue and representation or who have specific needs, reach out to them (e.g. through outreach activities in the areas where they live or cultural mediation*), adapt operating and communication methods (accessibility*, interpreting, etc.). They should be supported throughout their engagement, making sure that they are not infantilized;
- support and prepare all those who engage for others. This includes information*, training and concrete, emotional and financial support. This support should enable them to move from knowledge based on their own experience to knowledge based on collective experience;
- ensure that each party's contribution is able to influence the decision and be accountable for it throughout the project; as far as possible aim for joint decision-making;
- evaluate the actions carried out jointly throughout a project, in order to identify best collaboration practices* and aspects that can be improved. In particular, this evaluation includes the way in which participants perceive the consideration of their contributions.

Develop the various forms of engagement

➔ It is recommended to encourage and support the various forms of engagement of people for the benefit of their health, well-being or quality of life, or that of their peers* and for the quality of care and support.

Within personalised care or support activities

➔ It is recommended to encourage and support people's engagement in their own care or life projects, in particular by systematically taking into account their experiences and preferences*.

This involves achieving the following objectives:

- creating or reinforcing places of information and "mediation*", such as "user centres" or any other place that is genuinely close to stakeholders and is run by peers or associations;
- at these places of information, making the various types of information accessible and understandable to all: for example, patients' or carers' rights, academic knowledge and knowledge derived from the experience of stakeholders, etc.;
- for the formulation of a care or life project, developing the means to evaluate people's preferences and supporting shared decision-making; seek joint decision-making as far as possible;
- developing peer support in places of care and support (including in the home), whatever the form envisaged: peer support*, peer education*, peer navigation*, health mediation*, etc.;
- systematically ensuring the effective and operational presence of partner-patients* in patient therapeutic education* programmes, and of peers in health autonomy support* or health education* programmes, whether for the design, running or evaluation of the programmes.

* The words followed by an asterisk are defined in the glossary appended to this recommendation [in French].

Within structures and project management

- Irrespective of the status of the structures (public, private not-for-profit including associations managing establishments, private commercial, independent non-hospital practices), it is recommended to involve public in the management of services and the evaluation of practices. The aim is to integrate their perspectives*, experiences and knowledge in order to jointly construct avenues for improvement.
- It is recommended to set up environments conducive to free and fair expression and to stakeholder engagement *via* appropriate mechanisms or tools (surveys, focus groups*, equal representation of users/professionals in groups or bodies, etc.).
- With a view to joint engagement, it is recommended that the initiator of a project make known to all parties the aims and intentions of the project, along with the nature and level of involvement expected, to enable professionals and stakeholders to decide on their capacity to engage.

Aiming to improve the quality and safety of care or support

It is recommended:

- to integrate the experiences of stakeholders, both in the evaluation of social support practices and in the quality and safety of care (e.g. analysis of satisfaction data* or data from internal and external evaluations, activity reviews, avoidable adverse events*, tracer patients*, etc.);
- to systematically propose to users' representatives* and elected members of social councils (CVS)* that they collaborate in processes to evaluate practices and organisations, or even jointly construct these processes with them, while respecting professional confidentiality (for example, in the context of internal and external evaluations of social care establishments and services or the certification of healthcare establishments*);
- to develop health democracy* at the primary care* level, for example by encouraging the creation of users' committees in community care facilities (health centres, multi-professional health centres, etc.) and by structuring an organisation for dealing with complaints;
- to encourage and support the involvement of residents in territorial health strategies, such as local health contracts* (CLS), local mental health councils* (CLSM) or community-based approaches to health*. Similarly, to support the involvement of residents in schemes such as city health workshops (ASV), territorial health professional communities* (CPTS) or territorial support platforms* (PTA).

Within healthcare and social work professional training

- It is recommended that universities and training institutes (social work training institutes, nursing schools, etc.) encourage and support stakeholder engagement in the initial and lifelong training of health and social work professionals.

This involves achieving the following objectives:

- making available the human and financial resources required to structure and manage stakeholder engagement in training;
- developing training programmes for professionals in collaboration with stakeholders in order to include their experience and knowledge;

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- durably integrating peer trainers into pedagogical teams, in addition to association representatives, people elected to formal bodies (e.g. social council), and people receiving care or support who intervene occasionally;
- involving stakeholders who collaborate in training programmes in certain student assessment procedures (participation in juries, evaluation of dissertations, etc.).

➔ It is recommended to encourage and support stakeholder engagement in the construction of conference and seminar programmes and to encourage their involvement as conference participants or speakers. In the latter case, in addition to financial resources, there is often a need for support in the writing of summaries.

Within research and innovation design activities

➔ It is recommended that universities, research or evaluation bodies and companies promote stakeholder engagement in research or evaluation programmes and in the design of innovative health or social care solutions.

This involves achieving the following objectives:

- working more closely with stakeholders, their associations or collective bodies, to identify research and innovation priorities in order to ensure that, at the very least, they correspond to what really matters to stakeholders;
- ensuring the participation of stakeholders in committees for the evaluation and selection of research or innovation projects;
- conducting collaborative research[2] integrating stakeholders as co-researchers;
- valuing the experienced-based knowledge of stakeholders, and including them in social and healthcare intervention evaluation processes, in particular making use of qualitative study reviews;
- jointly specifying the nature of the contribution expected from stakeholders for the research project; specifying, in particular, at what stages stakeholders are involved: identification of needs, validation of themes, drafting of the protocol, collection and analysis of usage data*, checking of ergonomics*, review of documents, dissemination of results, etc.;
- collaborating with stakeholders, their associations or collective bodies or e-patients*, in the development of innovative connected objects, digital solutions or digital information platforms. This applies from the definition of objectives stage right through to their evaluation, including definition of the design and drafting of content.

Creating conditions that encourage engagement

Promoting autonomy and respecting individuals' rights

➔ It is recommended that all players in health and social care organisations, who wish to encourage or support forms of stakeholder engagement*, guarantee the exercise of their individual rights and freedoms.

This involves achieving the following objectives:

[2] Here, this refers to collaborative, participatory or community-based research.

* The words followed by an asterisk are defined in the glossary appended to this recommendation [in French].

- ensuring genuine stakeholder decision-making power and empowerment in order to avoid any manipulation;
- creating environments that provide people with the opportunity to:
  - express what they want or what does not suit them without fear (for example, with respect to the information given to them, the social or healthcare pathways offered to them, the way they are received, etc.),
  - make decisions that affect them, based on their own values and priorities, without being judged;
- adopting a kind and non-judgemental attitude that promotes stakeholder autonomy*, and taking care not to depersonalise * them;
- accepting that certain terms used to designate stakeholders may be perceived as derogatory or even humiliating, due to variable interpretations depending on the context of use (for example, the adjectives “abnormal”, “disabled”, “handicapped”, “deficient”, “mentally ill”, “old”, etc.). The terms used by the stakeholder to describe his or her situation should be discussed with him or her.

Obtaining strong institutional support

Implementing facilitating organisational structures

➔ It is recommended that the governing bodies* of structures provide visible and formal institutional support for stakeholder engagement (inclusion in the strategic projects of associations or institutions, in establishment or service projects, in the charter of values, in institutional communication, etc.).

➔ This support requires a long-term vision of projects and the provision of sufficient human and financial resources, in particular to ensure the sustainability of the engagement process, even when the people who initiated it leave.

➔ It is recommended that the governing bodies of organisations or project pilots remove resistance to stakeholder engagement and act on levers for change, for example by raising awareness of the partnership culture.

Incorporate stakeholder engagement in the human resources strategy

➔ In order to initiate and sustain the engagement process, it is recommended to support change management within institutions via a dedicated unit that provides coordination and methodological support:

- supporting this change requires sustained exchanges, particularly informal ones, between professionals and stakeholders;
- this unit can incorporate stakeholders who have acquired specific competencies to take into account the experience of their peers, through collective practice, a professional background or training.

➔ It is recommended that the status be clarified and that provision be made for compensation or remuneration for stakeholders who engage for others or for the quality of care and support. It is recommended that all costs incurred by individuals should be systematically reimbursed, even in the context of voluntary work (e.g. mandates of users' representatives* in healthcare institutions or elected members of social councils).

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Preparing and supporting users and professionals

- In order to limit the risks of token participation, it is recommended that the parties clarify together the objectives of the envisaged collaboration and clearly define the roles and responsibilities of each party, without setting them in stone. This facilitates their engagement, enables them to ascribe meaning to their actions and to increase their skills.
- It is recommended that teams be prepared to include people engaged in the quality of care and peer support (e.g. peer workers, peer educators, etc.). This involves, for example, discussing the expected benefits and the complementary roles of each party and providing time to reflect on practices.
- It is recommended to support people engaged for others and for the quality of care and support. This means making sure that this engagement does not represent too heavy a burden or make too many demands on them by encouraging exchange related to their experience of this engagement, their needs, the resources they lack and the difficulties encountered.

Training professionals and users in collaborative work and engagement-related concepts

- It is recommended that joint training times be organised for stakeholders, professionals and decision-makers in order to create a common culture and a shared language that will facilitate the implementation of partnerships.
- In both initial and lifelong learning, it is recommended that healthcare or social work professionals and stakeholders engaged for their peers should have been able to develop their skills through collective experiences (e.g. community life) or be trained:
  - in active listening*, collective leadership and co-construction* techniques;
  - in the collection and consideration of stakeholder expectations, needs, difficulties and experiences;
  - in the specificities of collaborative work and of partnership between professionals and stakeholders: it is a question of differentiating between a corporatist or militant approach and a collaborative approach, of understanding the value of experienced-based knowledge and of comparing the perspectives of stakeholders and professionals, of reflecting on the ethical aspects, and of knowing the conditions of the partnership, etc.;
  - in concepts related to individual engagement: empowerment*, health promotion*, health literacy*, etc.

These competencies must be modulated according to the needs inherent to their form of intervention and take into account specific care or support contexts (e.g. situation of disability, vulnerability, addiction, etc.).

Acting with method

- Upstream of any partnership, it is recommended that all the parties be involved in defining the objectives, ethical values or principles, the meaning of the terms used, the skills required, the operating methods and the role and place of each party, and to jointly agree the material resources envisaged and the deadlines.
- It is recommended to link, in a complementary way, the engagement of stakeholders, including when they appoint themselves as self-representatives*, with the engagement of representatives with mandates (members of social councils or user representatives*) and, more broadly, with the engagement of associations.

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- ➔ It is recommended that stakeholders make use of their own skills and expertise* in order to be able to make proposals on themes with which they feel comfortable.
- ➔ During the engagement process, it is recommended that the organisation and availability of stakeholders be taken into account, in the same way as professionals, by virtue of dialogue and the principle of non-domination.
- ➔ It is recommended that project steering bodies recognise the time needed to build a relationship, enter into dialogue and establish an agreement. Similarly, time should be allowed for familiarisation and preparation work with a view to meetings.

Evaluating the quality and effects of engagement

Evaluating the quality of engagement

- ➔ It is recommended that an evaluation of the engagement process, in whatever form, be carried out systematically and that this evaluation should:
  - focus on process and results elements, integrating the perceptions of both stakeholders and professionals;
  - be designed collectively with all engaged stakeholder categories. The aim is to work together to define evaluation questions, indicators, evaluation modalities as well as the use of the results.
- ➔ It is recommended that the conclusions of these evaluations be reported and that they be taken into account in processes for improving the quality of care and support (accreditation process, continuous quality improvement process, evaluation of establishments and services, etc.).
- ➔ It is recommended to promote inspiring experiences and to communicate them through different media (articles in the professional or mainstream press, websites, conferences, seminars, academic exchanges, action bases, podcasts, events, etc.).

Conducting research studies on engagement

- ➔ It is recommended that universities or research bodies develop research on the effects of engagement, both on the different types of players involved (professionals and stakeholders) and on the publics benefiting, as well as health and social care organisations and practices. Research questions and indicators need to be defined jointly between professionals, researchers and stakeholders.
- ➔ It is recommended that universities and research bodies also address factors for the success of engagement processes (what works, for whom, in what context, under what conditions), combining quantitative and qualitative methods.

The list of participants having contributed to the drafting of this recommendation and the method used to develop it are available in the rationale that accompanies this text [in French].

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This document presents the main points of the publication:

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